My name is Andy, I live in Leicester and I am treated at Leicester Royal. I am now officially 9 years living with stage 4 incurable lung cancer, having been diagnosed at the age of 41 years.

It all began in early 2016, when I noticed I was becoming short of breath every time I climbed a flight of stairs - something that felt out of the ordinary. I visited my local GP, but during my first two appointments, I was told it was likely indigestion and was advised to take over-the-counter remedies. After three months with no improvement, I returned for a third visit. This time, I saw a different doctor who listened to my chest with a stethoscope and immediately picked up on something concerning - I was only breathing from one lung. He arranged for a chest X-ray that same evening at the local hospital.

The scan revealed fluid on my right lung, and I was told I needed a procedure called a pleural effusion to drain it. A sample of the fluid was taken for testing, and I underwent a CT scan. At that point, I was reassured the fluid buildup was likely due to something relatively minor, like a water infection.

The following week, I returned to the hospital for the procedure, expecting it to be routine. I was alone—without any family or support when I was informed by the doctor, very directly, that he believed I had cancer that had metastasised, and was clearly visible on the CT scan.

It was a complete and devastating shock—especially hearing such life-altering news with no one there beside me for support. I felt physically sick. To this day, I struggle to understand why that conversation couldn't have waited until I had family support with me.

Further biopsies were taken, and the fluid was successfully drained. Not long after, I was introduced to my oncologist. I was informed that my cancer was ALK-positive - a genetic mutation that can help guide treatment decisions. The options were explained, and in October 2016, I began a clinical trial for a drug called *Brigatinib*. I was told it might help extend my life and was given a prognosis of around five years at most.

Remarkably, within just four weeks of starting Brigatinib, the tumours in my right lung had reduced in size by about 50%. They've remained stable and unchanged ever since. Being on a trial, I was receiving regular CT scans to the body and MRI scans to the head.

Then, in late 2017, an MRI revealed the cancer had spread to my brain. I was told I had 63 lesions in the brain and underwent full-brain radiotherapy. The recovery was tough, with difficult side effects, but after a few months I managed to return to living a very normal life.

For nearly 5 years, I remained on Brigatinib with no significant side effects. All lessons in head and body were stable throughout this time.

In 2022, I began noticing changes in the fine motor skills of my right hand. My oncology team suggested it was time to change treatment, and I was prescribed *Lorlatinib*. The initial 100mg dose caused severe mental side effects for me, so it was gradually reduced - first to 75mg, and then to 50mg, which I've remained on to this day with no further progression anywhere else.

It has to be said that throughout this journey, I've also explored complementary therapies, holistic treatments and made lifestyle changes to support my overall health and well-being.

I have met some wonderful nurses over the past 9 years but, unfortunately, I can't say the same about some oncologists.

Today, I'm still living a very full and active life. I am a professional guitarist with the Anthemics (available for functions!). We perform after each rugby international match at Twickenham Stadium to a mass audience and we have a booking for a private function at a top hotel in Fance in August. I also do a bit of cycling.

I feel incredibly fortunate to be alive at a time when cancer treatments are evolving rapidly. I don't take a single day for granted—and I continue to look forward, determined to make the most of every moment.

I truly believe that a positive mindset is one of the most powerful tools we have in facing this disease. And that's exactly how I plan to keep fighting, head on, with positivity, hope and strength.

Andy Kempin June 2025